



Evaluating Programs to Improve Social Acceptance of People with Mental Health Issues

October 21, 2008



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Mental Health Services
www.samhsa.gov

www.promoteacceptance.samhsa.gov



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*The Moderator for this call is **Holly Reynolds Lee**.*



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Questions?

At the end of the speaker presentations, you will be able to ask questions. You may submit your question by pressing *1 on your telephone keypad. You will enter a queue and be allowed to ask your question in the order in which it was received. On hearing the conference operator announce your name, you may proceed with your question.



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Speakers

Patrick Corrigan, Psy.D., Professor of Psychology and Associate Dean for Research, Illinois Institute of Technology

Patrick Corrigan is Professor of Psychology at the Illinois Institute of Technology and Director of the Joint Research Programs in Psychiatric Rehabilitation at IIT. The Joint Programs are research and training efforts dedicated to the needs of people with psychiatric disability and their families. Corrigan has been principal investigator of federally funded studies on rehabilitation, team leadership, and consumer operated services. Six years ago, Corrigan became principal investigator of the Chicago Consortium for Stigma Research (CCSR), the only NIMH-funded research center examining the stigma of mental illness. One current study funded by NIAAA, NIMH, and The Fogarty Center is examining the stigma of mental illness endorsed by employers in Beijing, Chicago, and Hong Kong. Corrigan is a prolific researcher having published ten books and more than 200 papers.



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Speakers

Jonathan Delman, JD, MPH, DSc (cand.), Executive Director, Consumer Quality Initiatives

Jonathan Delman is the founding executive director of Consumer Quality Initiatives. Mr. Delman is widely considered a national expert on behavioral health participatory action research, consumer directed survey research and quality management. He consults with SAMHSA, the Commonwealth of Massachusetts, M-POWER, and several universities on these topics, and is a featured speaker on these topics at national conferences. Of note, he has been co-chair of the President's New Freedom Commission work group on quality measures and information technology for acute care. In addition, he is a co-investigator for the newly funded grant from NIMH to Boston University School of Public Health to develop the Boston Mental Health Community-Academic Partnership. Mr. Delman, who lives with bipolar disorder, received a BA in economics from Tufts University, a law degree from the University of Pennsylvania, and a Master's of Science in Public Health from Boston University. He is currently a Doctoral candidate in Health Services Research at the Boston University School of Public Health. He has received several awards from the Massachusetts Department of Mental Health, and also received the Isaiah Ullis Public Advocacy from the Massachusetts Psychiatric Rehabilitation Association.



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Measuring Anti-Stigma Programs



Patrick Corrigan, Psy.D.
Illinois Institute of Technology
Chicago Consortium for Stigma Research



Goals for this Webinar

- Remind us of the social injustice of stigma (or promote inclusion and empowerment)
- Review ways to address stigma and empowerment
- Discuss how to assess anti-stigma programs

FACES OF THE ENEMY



REFLECTIONS OF THE HOSTILE IMAGINATION



The Psychology of Enmity

Sam Keen



NEW YORK POST

METRO

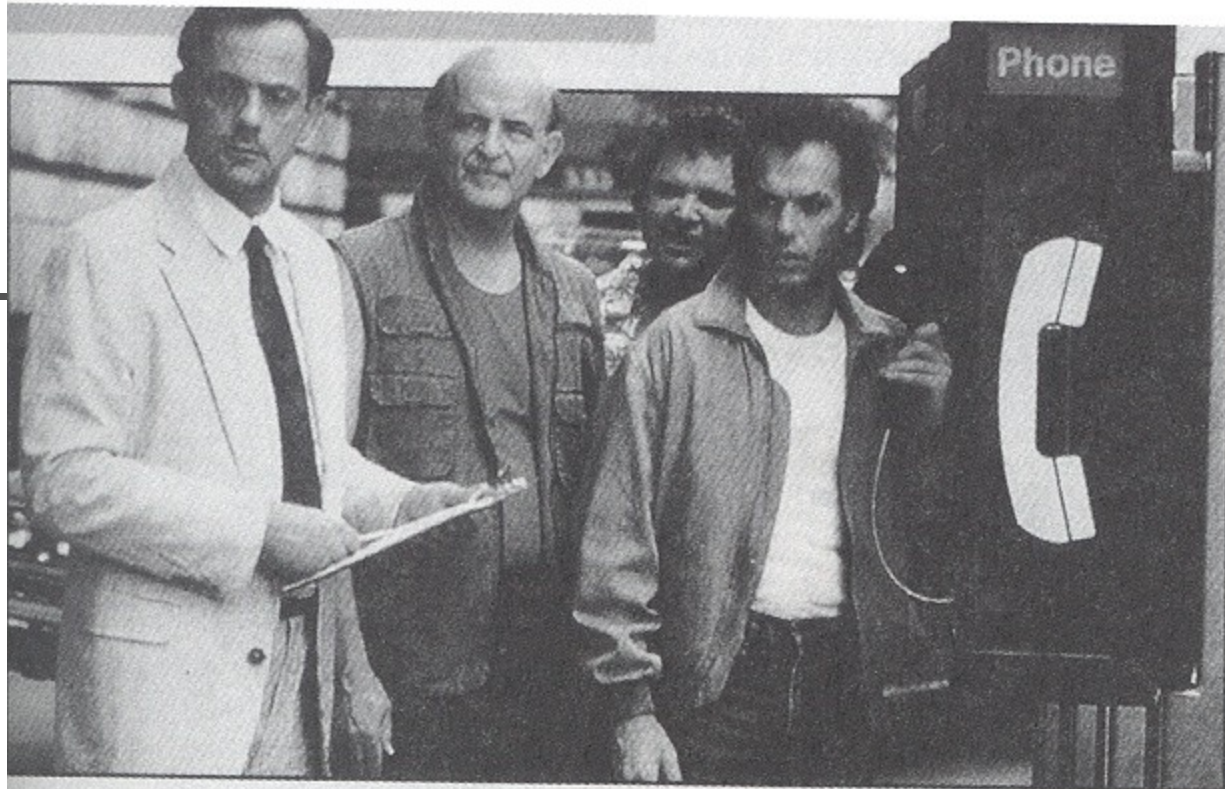
TRUTH

FRIDAY, MAY 9, 1980 30 CENTS

LARGEST-SELLING AFTERNOON NEWSPAPER IN AMERICA

640,000

FREED MENTAL PATIENT KILLS MOM



A motley group of lunatics scour New York.

Nutty Psychiatric Patients Are **THE DREAM TEAM**



The Impact of Stigma and Discrimination

1 Public stigma:

- the loss of rightful opportunities and community
- when the public endorses the stereotypes of mental illness
 - Stereotypes
 - Prejudice
 - Discrimination
 - Work, housing, health care, faith community
- Social Inclusion



The Impact of Stigma and Discrimination

2 Self-stigma:

- Internalized stigma
 - Aware of the stereotype
 - Agree with it
 - Apply it to self
 - Suffer the results / Shame
 - Low self-esteem and self-worth “I am not worthy of a good job!”
 - Low self-efficacy “I cannot handle a job!”
 - Why try “So why should I try to get a job!”
- Dignity and Empowerment



What Can We Do About it?

Public Stigma

- **Protest** Moral authority, don't think that way
 - Attitudes?
 - Behavior? Economic Power

- **Education** Myths versus facts
 - People with mental illness choose to be mentally ill

- **Contact**
 - Meet people with mental illness



What Can We Do About it?

Public Stigma

- More on contact
 - More than one time contact
 - Coming out of the closet
 - Contact with who?
 - The famous person
 - Our neighbor and co-worker



The Impact of Stigma and Discrimination

3 Label Avoidance

- I do not want to be labeled mentally ill
- So I won't go for services
 - Medication
 - Support
- Seeking and finding care (*poor insight*)
- Participation in services (*adherence!!!*)
- Empowerment

Changing Public Stigma

- Contact
 - Real people

“Meet Bob Lundin”



Robert Lundin
Project Coordinator

What Can We Do About it?

Self-Stigma

- Group identity and peer support
 - Consumer operated services
 - Mutual help
 - Joint advocacy
 - Drop-in centers
- Empowerment
 - Total decision making and self-determination
 - Supported services (employment, housing)



What Can We Do About it?

Label Avoidance

- Education
 - Stereotypes
 - Weak, to blame, scary, incompetent
- Easy and more private access
 - Leading to mental health literacy
 - About mental illness
 - About mental health service
- On line services
- In vivo partners (Active Minds)



What's Out There?

Current Programs

- World Psychiatric Association
 - www.worldpsychiatricassociation.org/sections/stigma/index.shtml
 - Programs by country (N>50)
- SAMHSA's Resource Center to Promote Acceptance, Dignity, and Social Inclusion
 - www.promoteacceptance.samhsa.gov/default.aspx
 - Programs by state (N>100)
- Canada Programs
 - *"...the Commission is launching a major, national 10-year anti-stigma and discrimination reduction campaign. This campaign will be the largest systematic effort to reduce the stigma of mental illness in Canadian history"*

Don't Call Me Nuts!

COPING WITH THE STIGMA OF MENTAL ILLNESS



- ◆ Dealing with the Pain of Self-Stigma
 - ◆ To Disclose or Not to Disclose
- ◆ Seven Ways to Foster Personal Empowerment
 - ◆ Changing Society's Reactions through Contact, Education, and Protest

Patrick Corrigan ◆ Robert Lundin

Public Service Announcements

what a difference a friend makes



<http://www.whatadifference.samhsa.gov/>



Media Watch



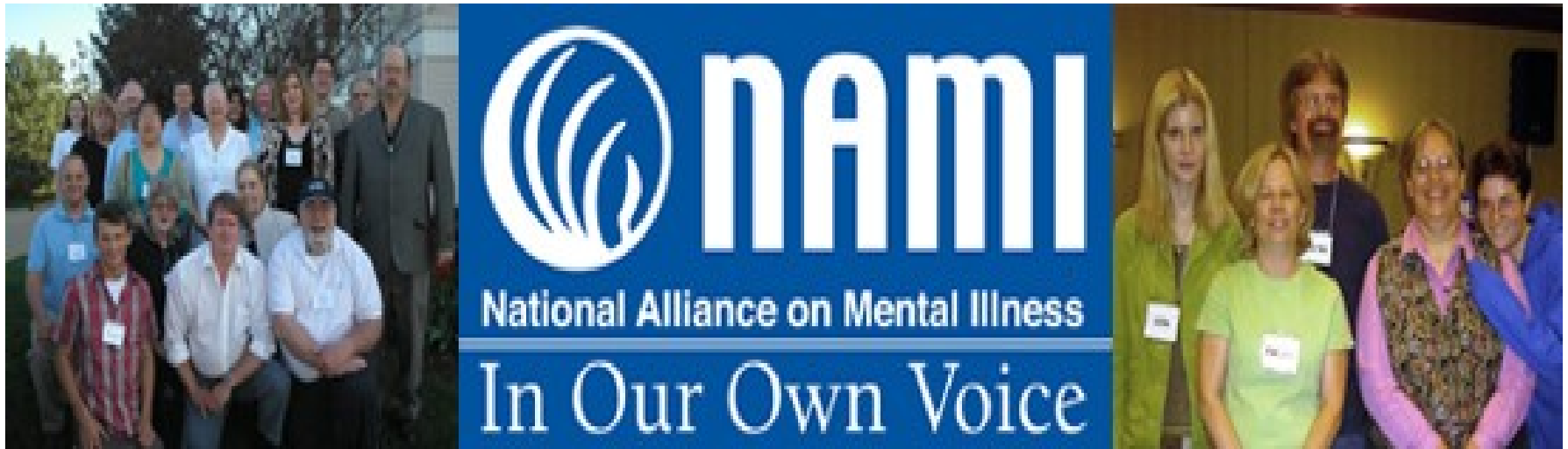
www.nami.org/stigma

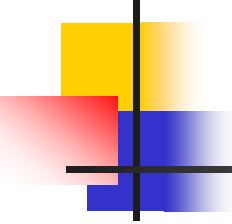
Fright Night Scream Park





Personal Stories





"There's a temptation for the Commission to sprint out of the gate with a mass marketing campaign, but that would be a mistake." (The Mental Health Commission of Canada on their Anti-Stigma Program.)

Ahead of the Data!
Intervene Now!



Evidence Based Considerations

- Public Stigma
- Self-stigma
- Label Avoidance

Beat the Stigma and Discrimination!
Four Lessons for Mental Health Advocates



Patrick W. Corrigan, Psy.D.





Evidence Based Approach

- **WHO** is to be targeted.
- **WHAT** needs to be changed.
- **HOW** will this be changed.
- **WHEN** will change occur
- **MEASURE IT**



Measure It

- Participatory Action Research
- Focus groups
- Key stakeholders



Measuring Public Stigma Change

The Attribution Questionnaire (AQ-27)

Vignette

Harry is a 30 year-old single man with schizophrenia. Sometimes he hears voices and becomes upset. He lives alone in an apartment and works as a clerk at a large law firm. He had been hospitalized six times because of his illness.

- 27 items
 - How dangerous would you feel Henry is?

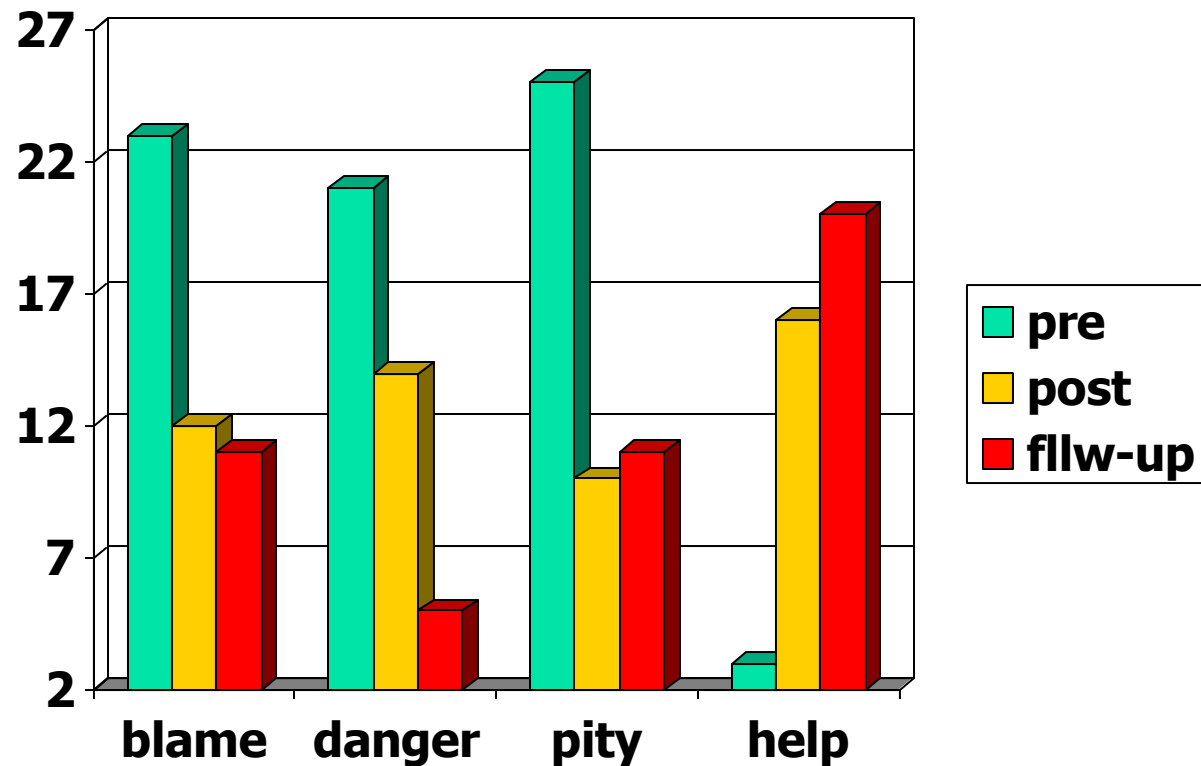
1	2	3	4	5	6	7	8	9
none								very much
at all								



AQ-27 subfactors

- Blame
- Anger
- Pity
- Help
- Dangerousness
- Fear
- Avoidance
- Coercion
- Institutionalize

The Mean or Average of AQ-Items





Evidence Based Considerations

- Reducing discrimination versus affirming actions
- Effect size and specificity
- Unit of measurement
- Process measurement
- Manuals and Fidelity
- Feasibility
- Cost effectiveness



Measuring Self-Stigma Change



Self-Stigma and Mental Illness Scale

"I think the public believes....."

- *..most persons with mental illness cannot be trusted*
- *..most persons with mental illness are unable to get or keep a job*

■ 40 items

1	2	3	4	5	6	7	8	9
none								very much
at all								

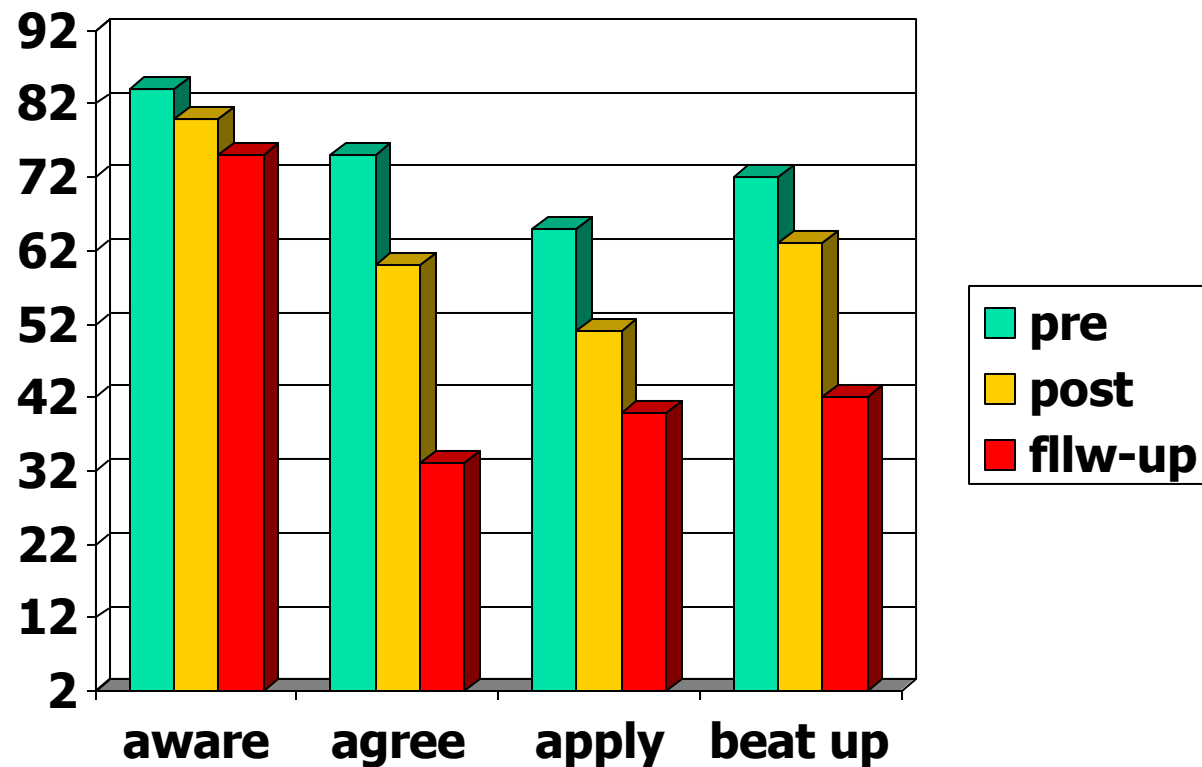


SSMIS subscales

Stereotype

- *..most persons with mental illness cannot be trusted*
- Aware *"I think the public believes....."*
- Agree *"I agree that people with mental illness ..."*
- Apply *"I have a mental illness and so I am..."*
- Aware *"I beat myself up when I believe I am..."*

The Mean or Average of SSMIS-Items





Getting Help

Stigma Change Methods

Catalogue existing programs

Support manual development

Training and fidelity

RFA development: for local stigma change

Evaluation Approaches

Research methods training

Consultation on methods

Mentoring young scientists

RFA development: to identify national change



The Chicago Consortium for Stigma Research

www.stigmaresearch.org

Funded by National Institute of
Mental Health

Effective Outcomes Evaluation at Little or No Cost

Jonathan Delman, MPH, JD, PhD (cand.)
Consumer Quality Initiatives, Inc.

Consumer Quality Initiatives, Inc.

A Massachusetts-based consumer-directed and staffed quality improvement, evaluation & research organization (www.cqi-mass.org).

CQI's Mission

To develop opportunities for the meaningful involvement of consumers and family members in all aspects of mental health research and program evaluation.

CQI's Mission

We aim to:

- Study issues that are relevant to the community
- Initiate changes to improve the system for all
- Narrow the gap between research/evaluation and practice.

Don't Wait for the Evaluation! Start Now!

- Know the potential value of your data (your bargaining chip). Academics need to keep up with the funding trends.
- Research which academic institutions (or specific professors) will be the best match for your needs. Talk to other community organizations who have worked with them.

Don't Wait for the Evaluation! Start Now!

- Develop relationships with academia/professor (e.g., sit on an advisory board, invite them to be on a board)
- Have institutional allies (eg. Funders, DMH)

Establish Ground Rules

Write out project plan

- Who is responsible for what tasks and outcomes
- Budget and payment arrangements (if any)
- Specific personnel
- Maintaining contact
- Methods of accountability

Establish Ground Rules

Reports

- Establish how will report(s) be used
- Establish ownership of data and reports

Establish the Relationship

- Times of informality—find it and use it
- Cross-training
 - Present to the other on
 - Who you are
 - What you do
 - Areas of expertise
- Debrief after new collaborative events
- Celebrate achievements

Outcomes Evaluation

- Are we producing what we're supposed to be producing?
 - Output (# of people who attend the presentation(s))
 - Short-term outcomes (attendees' knowledge, attitudes)
 - Long-term outcomes (attendees' knowledge, attitudes)

Evaluation Costs

➤ Financial Costs

- Salaries (% time) of people doing the work, examples:
 - Entering and checking data entry
 - Supervision of staff and volunteers
- Consultants (e.g., training for data collection and statistical software, evaluation strategies)
- Printing (e.g., surveys, reports)

Evaluation Costs

- Data collection
 - Purchase of survey instrument
- Data processing and analysis costs
 - Purchase of statistical software packages
- Travel and accommodations

➤ Opportunity Costs

- Time and resources that could be devoted to other activities

Deciding to Conduct a Particular Kind of Evaluation

- Cost/Benefit analysis: Is there a positive evaluation benefit in relation to the cost?
- Very difficult to determine, particularly with outcomes evaluations
 - Benefits:
 - What do you hope to gain from an outcomes evaluation?
 - What is the value of that gain (in monetary terms)?
 - What is the likelihood of achieving that gain, and how fully?

Keys to Low Cost Success

- Keep things simple
- Do not be ambitious
- Consider early investment in evaluation training and consulting
- Keep things simple
- Do not be ambitious
- Consider use of ongoing technical assistance

Low Cost Pre/Post evaluations

- Allows you to detect change
- Keep costs down by not having a comparison group
 - You will not be able to prove causation, though you can prove association
- Increase your N by using the same or similar instrument over a period of several interventions

Types of Instruments

- Mostly quantitative items (close-ended)
- Less than five response options per item
- Locate existing instruments (for public use)
 - Consult with researchers familiar with the topic
 - Review the literature
 - Google TM

Instrument Adaptation

- Adapt the instrument to meet your objectives and/or the practical needs of stakeholders (validity is relative)
- Keep it relatively short (shorter than research instruments)

Measures (to Simplify Analysis while Increasing Validity)

- Limit number of outcome domains
- Most “causal” outcome(s); examples:
 - Training - knowledge
 - Photovoice - attitudes
- Participant self-report, existing records, and/or staff ratings
- Domains and outcome measures should correlate strongly with intervention impact

Timing of Data Collection

Immediately before and after the event, training...

- Even a few days later raises costs significantly
- Attenuates the association with the intervention
- Lose your N (i.e. the percentage of people who attended) for post

Mode of Data Collection

- On the spot is cheapest
- Phone and mail are costly (time)
- Web can be a time saver, particularly if the organization and respondents have an ongoing relationship

Example:

CPS Training Evaluation

The Situation:

- 25-30 trainees go away for 5 days of intensive training, go home for the weekend, and come back for 3 additional days of training
- One month later they take an exam to become certified. They have the opportunity to receive tutoring over that month

Example:

CPS Training Evaluation

The Evaluation

- We adapted a survey developed by researcher Judith Cook to 15 knowledge items that were specifically addressed.
- Pre evaluation given as training begins. Post (same survey) was given 4 weeks after training completed (to assess retention) via mail.

Example:

CPS Training Evaluation

The Results

While the evaluation had many strengths, the major drawback was the low return (60%) on the post. Also, outcome by definition attenuated by other events over those 4 weeks.

Statistical Assessment

- For each time intervention offered, and overall
- Basic statistical significance testing
 - Teachable with use of basic statistical software (eg., SPSS)

Statistical Analysis

- Question by question analysis of change (e.g., in knowledge) in order to compare which impacts are strongest/weakest
 - Very useful in considering improvements in interventions

Reasonable Initial Investments

- Basic Training in evaluation concepts, particularly in the use of surveys and ethics
- Training for some in using statistical software, analysis, and report writing
- Statistical software
- Web-based data collection systems



More information

For more information, contact:

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Resources

The following items are available by contacting the ADS Center to request a copy.

An Attribution Model of Public Discrimination towards Persons with Mental Illnesses
By: Patrick Corrigan, Fred Markowitz, Amy Watson, David Rowan, and Mary Ann Kubiak

Beat the Stigma and Discrimination! Four Lessons for Mental Health Advocates
By Patrick Corrigan

The Self-stigma of Mental Illness: Implications for Self-esteem and Self-efficacy
By: Patrick Corrigan, Amy C. Watson, and Leah Barr

SSMI – 1 Survey by Patrick Corrigan *Attribution Questionnaire – 27* by Patrick Corrigan



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Resources

Can Antistigma Campaigns Be Improved? A Test of the Impact of Biogenetic Vs Psychosocial Causal Explanations on Implicit and Explicit Attitudes to Schizophrenia:
<http://schizophreniabulletin.oxfordjournals.org/cgi/content/abstract/sbm131v1>

Consumer Quality Initiatives: <http://www.cgi-mass.org/>

Talking about Mental Illness: An Evaluation of an Anti-Stigma and Educational Program in Hamilton, Ontario : <http://www.mooddisorders.on.ca/pdf/TAMI.pdf>





Survey

We value your suggestions. Within 24 hours of this teleconference, you will receive an e-mail request to participate in a short, anonymous online survey about today's training material. Survey results will be used to determine what resources and topic areas need to be addressed by future training events. The survey will take approximately five minutes to complete.

Survey participation requests will be sent to all registered event participants who provided e-mail addresses at the time of their registration. Each request message will contain a Web link to our survey tool. Please call **1-800-540-0320** if you have any difficulties filling out the survey online. Thank you for your feedback and cooperation.

Written comments may be sent to the Substance Abuse and Mental Health Services Administration (SAMHSA) ADS Center via e-mail at promoteacceptance@samhsa.hhs.gov.



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